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A Place at the Table: Having a Voice in HIV Planning and Decision Making

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Image



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The thought of [being an HIV advocate](#) can be intimidating. You know that you want to do *something*, but you may not know what to do or where to start. It can help if you understand that your voice is important. What you have to say as a person living with HIV is valuable and needs to be heard by those making decisions about how HIV funding is used, what HIV policies are put in place, how research studies such as [clinical trials](#) are conducted, and how AIDS service organizations are run.

You may think that you cannot influence or even meet the people making these decisions. However, because of the hard work of HIV advocates over the years, most agencies involved in HIV work now include people living with HIV. Many local and national HIV research networks, service organizations, and planning councils get advice from people living with HIV through advisory groups that let them know about issues that are important to the HIV community.

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The following is a list of groups you may want to consider joining. Participating in these groups can be rewarding, but it requires time and commitment. Before getting involved, it is important to find out what is expected of you.

Note: Most of the information below applies to the United States. While some of the groups listed (such as Institutional Review Boards) also exist in other countries, others (such as HIV Care Consortia) do not. Outside the US, contact a national AIDS organization in the country where you live to find out about advocacy opportunities (to find such an organization, see the Resources section).

Click above to view or download this fact sheet as a [PDF slide presentation](#)

Community Advisory Boards (CABs)

You can make a big difference in the effectiveness of an organization's Community Advisory Board.

AIDS service organizations (ASOs), clinical research sites, and some health centers have CABs. Each type of CAB includes people living with HIV and, sometimes, other community members who are affected by HIV, such as partners of people living with HIV. Different types of CABs do different things. You can find out who serves on The Well Project's CAB [here](#).

An ASO's CAB can provide valuable comments from people living with HIV about the services the organization offers. Many CABs are very active. Others do not meet often and have little effect on the direction of the agency. You can make a big difference in the effectiveness of an organization's CAB. Contact your local ASO to find out if it has a CAB and how you can join.

Government-funded [clinical trials](#) in the US must set up CABs to make sure that community interests about HIV research are heard at the local level. CAB members offer comments about studies, get research results and up-to-date information about ongoing trials, advocate for participants in the trials, and help to sign people up for trials.

CABs can offer a great deal to the HIV community. You can also benefit personally from participating in

a CAB. In addition to contributing to the community, you may make new friends and get a better idea of what the research project or service organization provides. You can also educate yourself, which may give you more information and skills if you are looking for a job. If you are not sure whether you have anything to offer the CAB, talk to people who are already CAB members. They may help you identify strengths that you did not know you had.

HIV Planning Councils and HIV Care Consortia

Depending on where you live in the US, you could get involved with a local HIV planning council or a state HIV care consortium. HIV planning councils and care consortia are groups set up to guide how US government funding from the [Ryan White Program](#) is spent. Each planning council and care consortium works differently. Many consist of members who have been appointed by the head of the organization that receives the funding, while others have a more open membership. Members may include medical providers, public health officials, staff from community-based organizations, and people living with HIV. Even if you are not a member, you can speak before the council or consortium about the needs of your community.

HIV planning councils are located in urban areas with a large number of people living with HIV. They set priorities for the distribution of government funding based on the services that are most needed by people living with HIV in that area. Members regularly attend full council meetings and usually participate on at least one council committee. You may spend four to ten hours a month on planning council work.

HIV care consortia are regional or statewide planning groups in more rural parts of the country. They try to provide a broad-based community response to the HIV epidemic in their region. They also try to ensure that high-quality, comprehensive health and support services are available to people living with or affected by HIV.

Most consortia meet at least every three months, and many members participate on at least one committee. You may spend one to five hours a month on consortium work. Contact your local council or consortium to find out about the application process. To find organizations that receive Ryan White program funding, click [here](#) (note: Part A = planning councils/urban areas; Part B = care consortia/state programs).

Institutional Review Boards (IRBs)

IRBs - also known as ethical review boards (ERBs) or independent ethics committees (IECs) - exist to protect participants in research studies and [clinical trials](#). They are made up of professionals such as health care providers, lawyers, statisticians, researchers, members of the clergy, or ethicists, as well as community advocates, and others. Any hospital or research center in the US that conducts clinical or behavioral studies must have an IRB. All studies are reviewed and approved by the IRB before they begin. The IRB protects study participants by making sure trials are safe and ethical (meet accepted standards for how human beings are treated). The IRB can stop a trial that is not run properly.

The Institutional Review Board protects study participants by making sure trials are safe and ethical.

Many countries other than the US have ethics committees designed to oversee studies in people and protect participants. The specific design and function of these committees or boards vary from country to country.

If you are interested in joining an IRB, be prepared to learn a lot and spend many hours reading trial designs, attending meetings, and talking with other IRB members. It is important that people living with HIV be involved in the IRB process so that other members and researchers hear your concerns. However, be aware that this is a big commitment. If you are new to community advocacy, an IRB is

probably not the easiest way to get started.

To find out about IRB opportunities and application requirements, contact clinical trial sites where you live.

- To locate HIV clinical trial sites near you go to
 - [CenterWatch](#) (trials around the world)
 - [HIV/AIDS Clinical Trials Networks](#) (US National Institutes of Health)

Boards of Directors (BOD)

All not-for-profit ASOs have a BOD. The BOD has legal and financial responsibility for the organization. It also sets policy, hires and fires the executive director, and makes sure that the organization is serving its chosen mission. If the BOD has few or no members living with HIV, it may know less about the concerns and challenges of the people it is meant to serve. You can find out who serves on The Well Project's BOD [here](#).

One of the main responsibilities of the BOD is the financial stability of the organization. Many boards therefore require members to give or raise a certain amount of money. Some BODs make exceptions so that they can include people who cannot help to raise money, but who have other valuable things to offer.

Most BODs meet monthly or every other month for a couple of hours. Board members may spend two to four hours a month in meetings and other activities. If you would like to join the board of a local ASO, set up a meeting with the board's chairperson (sometimes called the president) or the organization's executive director.

Tips for Successful Advocacy

Community involvement is an important way of helping HIV groups serve their purpose. Being an advocate on a board or planning council can be very rewarding. It allows you to give your opinion and stand up for what you feel is important to you and your community. However, it also adds extra responsibilities and takes up some of your time. The following tips may help you to balance your physical and emotional health with your advocacy efforts:

- Remember you and your health come first.
- Think about what you would like to achieve before you join a group.
- Avoid taking on too many projects and limit yourself to only those you think you can complete.
- Find people to work with who understand the issues and will support your efforts.
- Try not to let disagreements become personal. Conflict is often a necessary part of any kind of advocacy, and you may meet resistance to your ideas. Try to stay focused on the issue even if you feel that you are being personally attacked.
- Learn from long-time advocates.
- Think before you speak. It can be scary to speak up, especially the first time you disagree with someone in power. Think about how you might feel beforehand so that you are prepared.
- Be careful not to let advocacy become an opportunity to give yourself power over other people.
- Respect the privacy and opinions of other advocates living with HIV.
- Recognize that you have a voice and ideas to add to the work that has gone before. At times, you may feel shut out by some people who have been involved in HIV advocacy for many years. Your experiences are valid.
- When choosing a board or planning council to join, look at who is already there. Are most of the people on the board or council similar to you (e.g., white cisgender women)? If so, consider whether/how you might help bring in people with different experiences.

Additional Resources

Select the links below for additional material related to community advocacy.

- [Positive Women's Network - USA](#)
- [Advocates for Youth](#)
- [HIV Prevention Trials Network \(HPTN\): Community Engagement](#)
- [Community Advisory Board Fact Sheet \(HIV Prevention Trials Network, PDF\)](#)
- [Resources for Advocates \(The Women's Collective\)](#)
- [Women/Women's Resource Advocacy Connection \(Center for HIV Law & Policy\)](#)
- [Peer Advocacy \(WORLD\)](#)
- [Make It Matter: 10 Key Advocacy Messages to Prevent HIV in Girls and Young Wome...](#)
- [Advocacy Tool Kit on Pediatric HIV Treatment \(Elizabeth Glaser Pediatric AIDS F...](#)
- [Community Advisory Board Best Practices & Recommendations 2013 \(HIV Health & Hu...](#)
- [Lesson 3: What Are IRBs? \(US Department of Health and Human Services\)](#)
- [Community Advisory Board Getting Started \(HIV Health & Human Services Planning ...](#)
- [FAQs \(San Francisco HIV Community Planning Council\)](#)



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